

## The Quality of Life of a Patient With Colostomy

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### Abstract

**Aim:** The aim of this research was to examine the quality of life of patients with temporary or permanent colostomy regarding age, gender, marital status and time spent with an ostomy.

**Materials and Methods:** The study involved 41 members of the Ostomy ILCO Clubs in Slavonski Brod and Osijek as respondents. The standard version of the "Quality of Life Questionnaire for a Patient with an Ostomy" was used as the research instrument.

**Results:** The mean value of the overall scale was 5.4. The respondents rated the physical well-being the highest, a median of 5.9 (interquartile range 4.6 to 7.2), and social well-being the lowest, median 5.0 (interquartile range 4.1 to 6). Women gave higher marks for physical, social and spiritual well-being, and overall for the scale median of 5.5 (interquartile range 4.9 to 6.1), but with no significant differences compared to men. Married respondents ranked psychological, social and spiritual well-being higher, with a median of 5.4 (interquartile range 4.7 to 6.0), but with no significant differences compared to those who live alone. Physical, psychological and spiritual well-being is somewhat lower in patients under the age of 65, and social well-being is lower in subjects aged 66-75, the median of 4.7 (interquartile range 3.6 to 5.6). Correlation between the subscales pertaining to quality of life of the respondents with regard to their age and with regard to living alone (single, divorced or widowed) is significant in terms of the physical (Spearman coefficient of correlation  $\rho = 0.945$ ,  $p < 0.001$ ), mental (Spearman coefficient of correlation  $\rho = 0.943$ ,  $p = 0.005$ ), social (Spearman's correlation coefficient  $\rho = 0.829$ ,  $p = 0.042$ ) and spiritual well-being (Spearman coefficient of correlation  $\rho = 0.886$ ,  $p = 0.019$ ).

**Conclusion:** Quality of life of patients with an ostomy is satisfactory. There are differences in quality of life regarding age, gender, marital status and time spent with an ostomy. There is also a connection between the subscales "quality of life regarding age" and "quality of life regarding marital status" of patients with colostomy.

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## Introduction

Year in, year out, cancer incidence and mortality rate are increasing worldwide. Colorectal cancer accounts for more than 9% of the world's cancer incidence. It is the third most common cancer in the world and the fourth most common cause of death (1). Globally, colorectal cancer (CRC) is the third most common cancer diagnosed in men (after lung cancer and prostate cancer), and the second most commonly diagnosed in women (after breast cancer) (2).

Carcinoma is the second most significant cause of death in Croatia: every fourth resident dies from cancer. Compared to other European countries, Croatia is a country with a medium incidence but high mortality rate (3). Colorectal cancer is usually caused by changes on the colon mucous membrane or on a polyp protruding from a mucous membrane (4). Like all cancers, it is most curable if detected at an early stage of the disease.

In many cases a surgical operation is performed that ends with the creation of a colostomy on the lower left side of the abdominal wall, but it is also possible to create an ostomy on the right side of the abdominal wall. In most cases, the colostomy is temporary and is removed but sometimes remains a permanent solution in cases of poor operation outcome and metastases (5). The main purpose of creating an ostomy is to release the stool and gas, that is, to keep the continuity of the digestive tract (2).

Before surgery, the patient often feels anxiety, worry and fear, and this is where a nurse plays a major role. Health education always begins with preoperative psychological preparation of the patient, as it allows the nurse to assess the patient's level of knowledge of the illness and operation itself, as well as about their family support, work, hobbies, cultural and spiritual beliefs. The success of mental preparation depends largely on the patients themselves and their acceptance of the new situation. If a patient cannot care for him/herself, the education involves a spouse or a family member (6).

Hospital discharge planning requires team work of doctors, nurses, enterostomal therapists and dieticians. At the discharge, patients and caregivers are provided with special information on the proper way of treating the ostomy and the surrounding skin, changing ostomy bags and using ostomy aids. Discharge information also includes instructions about prevention of possible complications. Family members participate in the process of cleaning the wound and skin and in changing ostomy bags so they can do it themselves when the patient returns home. Patients also get clear directions about when they need to call a doctor (7). The quality of life of a patient with colostomy depends to a great extent on how well they and their family have adopted procedures important for ostomy care and accepted the new lifestyle (6).

Although a minor surgery from the medical point of view, the creation of temporary or permanent ostomy greatly reduces the quality of the patient's life (8). Colostomy has a significant effect on the life of the patient, regardless of the diagnosis of the disease. Cohen et al. emphasize that for patients with cancer, concern about the creation of the ostomy goes beyond all the other patients' concerns (9). The influence of colostomy on physical, psychological, social and spiritual well-being is not unexpected, but is insufficiently described in the literature.

Research shows that quality of life is increasingly recognized as an important measure of the outcomes in survivors of large surgical and medical treatments. In patients with colon cancer, various physical problems are present after surgical treatment, such as problems with the stool and urination, and problems with intimacy, which significantly affects the quality of life. Evaluating the quality of life is considered crucial for evaluating clinical outcomes after surgical treatment since it considers the patient's perspective in the decision-making process (10).

New studies have shown that the ostomy has, as expected, a great influence on the patient's quality of life and a great influence on the patient's daily life. The easiest way to find out how an individual perceives his or her quality of

life and how satisfied they are with their everyday life after the creation of an ostomy is to use an interview or a questionnaire that assesses the quality of life (11).

The quality of life is multi-dimensional, dynamic, and subjective. It is focused on the patient, involving physical, functional, emotional and social/family well-being. This is why quality of life is important for assessing the effects of disease on individuals, their families and their community (12).

Many studies have shown a reduction in the quality of life in patients with colostomy. Dissatisfaction with preoperative preparation and postoperative care, complications related to ostomy, psychiatric history of the patient, and negative thoughts and beliefs associated with ostomy contribute to the reduction of life quality (13). On the other hand, ostomy gives many people hope, prolongs their life, and enables their activity and realization of life plans.

Adaptation to a new life situation lasts from several months to two years and is conditional upon a number of factors that include one's general health but also the level of knowledge and skills that the person possesses. The support of patient's family and health care professionals, as well as joining support groups where they will be able to talk about difficulties and identify with people who have experienced the same situation, is particularly important. All this enables the patient to restore their everyday activities and social roles as soon as possible (14). The patient's attitude toward their own well-being and functional status is an important outcome and the priority of each research.

According to the guidelines on care quality provided by the Swedish National Health and Social Care Board, the patients should be treated respectfully; they must receive satisfactory information and have the opportunity to participate in the decision-making process. Quality of life is essential for patients with colostomy and the factors that affect it should be enabled. Assessing the quality of life of patients with an ostomy will lead to a better understanding of the patients and improve their life quality. Psychosocial needs as

well as their impact on quality of life have been researched, but a small number of studies point to interventions which could solve problems and meet the needs of patients with a colostomy (1, 10).

The main purpose of this study was to examine the quality of life of patients with a temporary or permanent colostomy. Specific goals were focused on the following issues: a) to examine whether there is a difference in the quality of life of patients with temporary or permanent colostomy with regard to the respondents' age; b) to investigate whether there is a difference in the quality of life of patients with temporary or permanent colostomy with regard to the patients' gender; c) to find out whether there is a difference in the quality of life of patients with temporary or permanent colostomy given the respondents' marital status, d) to examine whether there is a difference in the quality of life of patients with temporary or permanent colostomy regarding the time spent with a colostomy and e) to find out whether there is a correlation between the "quality of life of patients with colostomy" subscales and their age, gender, marital status and time spent with a colostomy.

## Materials and Methods

Our respondents, a total of 41, were members of Ostomy ILCO Club Slavonski Brod and Ostomy ILCO Club Osijek who have either a temporary or a permanent colostomy. Subjects were aged 44 to 74, and there were both male and female respondents. All respondents were regular at their monthly Ostomy Club meetings.

As an instrument of research, an anonymous questionnaire was used, consisting of general demographic data (age, gender, marital status, temporary / permanent colostomy, how long a person has had a colostomy). The questionnaire used to assess the quality of life of a person with a colostomy was the "Quality of Life Questionnaire for a Patient with an Ostomy", City of Hope and Beckman Research Institute (9, 15, 16). This questionnaire consists of 43 questions evaluating the quality of life using a scale from 0 to 10. The questionnaire is divided into four

subscales: "Physical well-being" (questions 1 to 11), "Psychological well-being" (questions 12 to 24), "Social well-being" (questions 25 to 36), and "Spiritual well-being" (questions 37 to 43). Answers are scored, with 0 being the worst possible result, and 10 the best possible one. However, a few answers are scored in the opposite direction, with 0 being the best and 10 the worst result. Particles 11-12, 15, 18-19, 22-30, 32-34, and 37 are scored reversely.

The results were obtained by adding points to each particle in the subscale, then dividing the sum by the number of particles in each subscale. The total QOL score was obtained by summing the results of all the particles and dividing by the total number.

### *Statistical analysis*

Categorical data were represented by absolute and relative frequencies. Numerical data were described by the median and the limits of the interquartile range. The normality of the distribution of numeric variables was tested by the Shapiro-Wilk test. Differences in numeric variables by gender and marital status, due to deviations from normal distribution, were tested by the Mann-Whitney U test. The difference in numeric variables by age groups and duration of the ostomy, due to the deviation from the normal distribution, was tested by the Kruskal-Wallis test. All P values were two-sided. The level of significance was set at  $\alpha = 0.05$ . For statistical analysis, the statistical program MedCalc (version 16.2.0, MedCalc Software bvba, Ostend, Belgium) was used.

### *Ethical principles*

Prior to the research, a written consent of the Commission for Ethical and Vocational Issues at the J. J. Strossmayer University of Osijek, Faculty of Medicine Osijek was obtained (Class: 602-04/16-08/15, No.: 2158-61-07-1683, 10<sup>th</sup> June 2016.). The approval for the use of the standard questionnaire "Quality of Life Questionnaire for a Patient with Ostomy" was obtained from the City of Hope National Medical Centre Principal, Marcie Grant.

The research was conducted in accordance with ethical principles and human rights in research.

## **Results**

The study included 41 respondents aged 44 to 74 (mean age 66 years, interquartile range 61 to 74 years). Out of the total number of respondents, 26 (63%) were male and 15 (37%) were female patients. Most of the subjects were married, a total of 35 (85%). There were 6 (15%) patients with a temporary colostomy and 35 (85%) patients with a permanent colostomy. The patients' time spent with the colostomy was 1 to 360 months (mean 48 months, interquartile range 12 to 102 months).

The overall quality of life of the examinees with the colostomy includes physical, psychological, social and spiritual well-being. The full-scale reliability coefficient, Cronbach Alpha, was 0.957.

When it comes to physical well-being, 5 respondents (12.2%), had serious sleep problems, followed by problems with smells – 3 (7.3%) of them, and 2 (4.9%) of them reported problems with diarrhea. Problems with itching or pain, diarrhea, gases, leakage of the bag contents, and constipation / absence of stool, were the least apparent.

Regarding their psychological well-being, 6 (14.6%) respondents expressed fears that their illness would relapse. Also, it was difficult for them to adjust to the ostomy, and they reported a feeling of uselessness. Some respondents feel embarrassed by having a colostomy, some consider the ostomy hard to look at and take care of, some have memory problems and some of them do not feel happy with their lives as a consequence.

Regarding overall results pertaining to the social well-being components, privacy in the care of the ostomy is not a problem for most respondents. Nevertheless, for ten (24.4%) respondents, their condition is completely stressful for the family; six (14.6%) respondents state that their ostomy is a problem during travel, and five (12.2%) respondents report troubles with sports activities and recreation. As for the results of the participants with respect to

**Table 1.** Rating of subscales and the overall scale of the quality of life with a colostomy by age of respondents

	Median (interquartile range) according to age groups				p*
	Up to 65 years (N=18)	66 – 75 years (N=16)	76 and over (N=7)	In total (N=41)	
<b>Physical well-being</b>	5.7 (4.6 – 6.8)	6.5 (4.5 – 7.1)	6.7 (4.5 – 8.2)	5.9 (4.6 – 7.2)	0.671
<b>Psychological well-being</b>	5.1 (4.1 – 5.8)	5.3 (4.8 – 5.8)	5.8 (5.2 – 6.4)	5.2 (4.8 – 5.8)	0.385
<b>Social well-being</b>	5.0 (4.4 – 6.1)	4.7 (3.6 – 5.6)	5.1 (4.3 – 7)	5.0 (4.1 – 6.0)	0.364
<b>Spiritual well-being</b>	4.9 (3.9 – 5.9)	5.5 (4.3 – 6.3)	5 (2.9 – 6.1)	5.3 (4.1 – 6.1)	0.444
<b>Overall scale</b>	5.3 (4.7 – 6)	5.3 (4.8 – 5.9)	5.6 (4.6 – 7)	5.4 (4.7 – 6.0)	0.727

\* Kruskal Wallis test

**Table 2.** Rating of subscales and the overall scale of the quality of life by the length of time a person has spent living with a colostomy

	Median (interquartile range) according to the length of time spent with a colostomy				p*
	Up to 2 years (N=16)	From 3 to 10 years (N=19)	For 11 or more years (N=6)	In total (N=41)	
<b>Physical well-being</b>	6.1 (4.8 – 7.4)	5.4 (4.3 – 6.7)	7 (5.5 – 7.8)	5.9 (4.6 – 7.2)	0.255
<b>Psychological well-being</b>	5.2 (4.4 – 5.7)	5.2 (4.8 – 5.8)	5.5 (5.2 – 5.8)	5.2 (4.8 – 5.8)	0.413
<b>Social well-being</b>	5.1 (4.2 – 6.1)	4.8 (3.2 – 5.3)	5.9 (4.8 – 6.8)	5.0 (4.1 – 6.0)	0.110
<b>Spiritual well-being</b>	4.7 (4.1 – 6)	5.4 (4.3 – 6.1)	4.6 (3.6 – 7.3)	5.3 (4.1 – 6.1)	0.657
<b>Overall scale</b>	5.3 (4.7 – 6.2)	5.3 (4.4 – 5.6)	5.6 (5.3 – 6.2)	5.4 (4.7 – 6.0)	0.489

\* Kruskal Wallis test

the aspects of spiritual well-being, seven respondents (17.1%) find that they have a reason to live, whereas four (9.8%) respondents state that they are completely uncertain about their future. The same number of respondents find prayer and meditation sufficient to satisfy their spiritual needs.

In order to determine the differences in the quality of life with a colostomy in terms of age of

the respondents, they were divided into three groups: the first group with respondents of up to 65 years of age, the second one with those between 66 and 75 years old, and the third group with respondents older than 76 years of age (Table 1).

Analysis of the impact of time spent with an ostomy on the quality of life with respect to physical well-being, mental well-being, social



**Table 3.** Rating of subscales and the overall scale of the quality of life of a person with a colostomy

	Median (interquartile range)	Minimum - maximum
Physical well-being	5.9 (4.6 – 7.2)	1.5 – 9.3
Psychological well-being	5.2 (4.8 – 5.8)	3.4 – 7.5
Social well-being	5.0 (4.1 – 6.0)	0.9 – 7.4
Spiritual well-being	5.3 (4.1 – 6.1)	1.9 – 8.6
Overall scale	5.4 (4.7 – 6.0)	3.0 – 7.4

**Table 4.** Assessment of the correlation between the age of the subjects and the length of time spent living with a colostomy, according to marital status

	Spearman coefficient of correlation (p-value)					
	Age of respondents	Length of life with colostomy	Physical well-being	Psychological well-being	Social well-being	Spiritual well-being
<b>Married</b>						
Physical well-being	0.082 (0.638)	-0.103 (0.554)	-			
Psychological well-being	-0.038 (0.829)	0.112 (0.520)	0.118 (0.500)	-		
Social well-being	-0.139 (0.426)	0.027 (0.879)	0.683 ( <b>&lt;0.001</b> )	0.350 (0.040)	-	
Spiritual well-being	-0.036 (0.838)	0.028 (0.874)	-0.211 (0.224)	0.137 (0.432)	-0.083 (0.637)	-
Overall scale	-0.140 (0.423)	-0.032 (0.856)	-	-	-	-
<b>Living alone (single, divorced, widower)</b>						
Physical well-being	0.945 ( <b>&lt;0.001</b> )	0.543 (0.266)	-			
Psychological well-being	0.943 (0.005)	0.371 (0.468)	0.943 (0.005)	-		
Social well-being	0.829 (0.042)	0.543 (0.266)	0.829 (0.042)	0.714 (0.111)	-	
Spiritual well-being	0.886 (0.019)	0.429 (0.397)	0.886 (0.019)	0.943 (0.005)	0.829 (0.042)	-
Overall scale	0.987 ( <b>&lt;0.001</b> )	0.543 (0.266)	-	-	-	-

well-being, and spiritual well-being, is shown in Table 2.

Respondents rated physical well-being the highest, with a median of 5.9 (interquartile range 4.6 to 7.2), ranging from 1.5 to 9.3, and gave the lowest scores for social well-being, a median of 5.0 (interquartile range 4.1 to 6), ranging from 0.9 to 7.4 (Table 3).

There is a significant correlation between the quality of life subscales according to the respondents' age for those living alone (single, divorced or widowed) in terms of their physical (Spearman coefficient of correlation  $\rho = 0.945$ ,  $p < 0.001$ ), mental (Spearman coefficient of correlation  $\rho = 0.943$ ,  $p = 0.005$ ), social (Spearman's correlation coefficient  $\rho = 0.829$ ,  $p = 0.042$ ) and spiritual well-being (Spearman coefficient of correlation  $\rho = 0.886$ ,  $p = 0.019$ ). The overall scale is related to the age of the respondents (Spearman's coefficient of correlation  $\rho = 0.987$ ,  $p < 0.001$ ).

Physical well-being is significantly associated with psychological well-being (Spearman coefficient of correlation  $\rho = 0.943$ ,  $p = 0.005$ ), social well-being (Spearman correlation coefficient  $\rho = 0.829$ ,  $p = 0.042$ ) and spiritual well-being (Spearman coefficient of correlation  $\rho = 0.886$ ,  $p = 0.019$ ). Spiritual well-being is significantly and strongly associated with psychological (Spearman's coefficient of correlation  $\rho = 0.943$ ,  $p = 0.005$ ) and social well-being (Spearman coefficient of correlation  $\rho = 0.829$ ,  $p = 0.042$ ) (Table 4).

## Discussion

The overall quality of life of patients with a colostomy involves physical, psychological, social and spiritual well-being.

In the context of physical well-being, the results of this study show that respondents are most concerned with sleep problems, smells and diarrhea. They have least problems with itching or pain, gases, leakage of the bag contents, and constipation / absence of stool. In the research conducted by Grant et al., the subjects complained most of gas problems, smell,

diarrhea and leakage of the bag contents (17). In the study of Krouse, Herrington et al., it was reported that subjects had the most problems with the skin around the ostomy, with unpleasant smells and leakage of the bag contents (18). In the research conducted by Dabirian et al., the respondents complained about the skin around the ostomy, sleeping problems, unpleasant smells and gases (19). It is evident that, in addition to all the physical problems mentioned, all respondents (both in the present study and in other ones), complained about the smell. Pittman et al. point out that these problems can lead to psychological and social problems (20).

The results of this research with regard to psychological well-being of persons with a colostomy are supported by the results of earlier studies. Thus, for example, Krouse, Grant et al., state that most of the subjects experience problems with anxiety, getting to know new people, and fearing the return of the disease (21). Krouse, Herrington et al. report that the survey respondents complained most about having problems when they wanted to travel somewhere because they lacked privacy in maintaining the ostomy and therefore felt anxious (18). Mitchell et al. find that subjects in their research felt anxious and depressed (22). Orbach and Tallent state that dissatisfaction with one's appearance may last for 5 to 10 years after surgery (12).

In the context of social well-being, the results of our research show that privacy in maintaining the ostomy is not a problem for most respondents. However, most patients reported that their condition was completely stressful for their family. Some of them stated that their ostomies disturbed their intimacy or posed problems in sports and recreation, which is consistent with the results of other studies (17, 18, 20, 21). In research results of Mitchell et al. we can find that respondents felt isolated from society (22).

The results of this research show that, in the context of spiritual well-being, most respondents feel that they do have a reason to live. Some of them are completely uncertain

about their future, while others find prayer and meditation to be enough to satisfy their own needs. Conversely, in the research by Grant et al., the number of respondents who stated that they have a reason to live was the smallest. Similar to the findings of our study, respondents in Grant et al. research are uncertain about their future, but have religious support, and inner peace (17).

In the research of Krouse, Grant et al., the greatest problems are related to inner peace, reasons for living, and religious support (21). Dabirian et al. stated in their findings that the most problematic issue for their respondents was the conduct of religious activities, i.e. going to worship (19). In the research of Mitchell et al., patients are least likely to find hope for the future (22).

The nurse, as one of the persons who play a role in health education, provides the patient with physical and psychological preparation. In this process, the most important thing is to include family members and spouses. Given that both before and after surgery the patients feel anxious, afraid and worried about the outcome, the nurse must have patience and be extremely sympathetic to their health problems, including those pertaining to their physical, psychological, social and spiritual well-being. The nurse also provides support after the setting up of the colostomy, provides patient and family education and psychological support, and helps with the patient's participation in an ostomy club, so that the patient understands that he is not alone.

## Conclusion

Quality of life of patients with a colostomy is satisfactory. Physical, psychological and spiritual well-being is somewhat lower in subjects aged 65 and under, and social well-being is lower in subjects aged 66 to 75 but with no significant differences in other age groups. Women have given somewhat higher grades for their physical, social, and spiritual well-being, and for overall scale, but without any significant differences in relation to men. Married respondents have ranked their psychological, social and spiritual

well-being as well as the overall scale higher, but without any significant differences in relation to those living alone (single, divorced, widowed). The assessment of physical and social well-being is the lowest in patients living with an ostomy for three to ten years. Spiritual well-being is graded the lowest in respondents living with an ostomy for up to two years, while assessments of psychological well-being are equal according to the time spent living with a colostomy. Although present, the differences are not statistically significant. There is also a connection between the subscales "quality of life regarding age" and "quality of life regarding marital status" of patients with an ostomy.

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